



**Testimony to the Public Health Committee
March 2nd, 2016
By Leslie Simoes, Executive Director, The Arc Connecticut**

Testimony: Raised Bill 294 AN ACT CONCERNING SERVICES FOR INDIVIDUALS WITH INTELLECTUAL DISABILITY.

Thank you Senator Gerratana, Representative Ritter and members of the Public Health Committee for the opportunity to testify this afternoon.

My Name is Leslie Simoes and I am the executive director of The Arc Connecticut. The Arc is a 63-year old advocacy organization committed to protecting the basic civil basic rights of people with intellectual and developmental disabilities and to promoting opportunities for their full inclusion in the life of their communities. We are part of The Arc of The United States. Nationwide there are 675 chapters in 49 states with about 4700 service locations. Across the country we have about 6900 board members, 124,000 staff, more than 46,000 volunteers and collectively we serve more than 1 million people - individuals with intellectual and developmental disabilities or I/DD and their family members.

Here in Connecticut there are 18 chapters with a total revenue of about \$103 million dollars. There are more than 195 board members, 3,729 staff and more than 1,288 volunteers.

The Arc was formed more than sixty years ago when parents of individuals with I/DD started organizing all around the country, in living rooms, church basements, in true grass roots fashion, with the goal of creating a better life for their sons and daughters with I/DD. Last week The Arc Connecticut in conjunction with the Connecticut Intellectual & Developmental Disability (I/DD) Caucus hosted a Family Action Day and over 150 families, advocates, individuals with disabilities and providers came to the capitol to lobby their legislators about the proposed budget.

In a budget year fraught with massive deficits and looming cuts that will not only hurt families but destroy what is left of a fractured support system, The Arc asked for this bill to be raised to provide relief to families that will not cost the state anything. We asked the committee to raise this "Families Rights Bill" because we hear from families, day in and day out and we hear from a wide variety of families with a variety of different needs who are struggling. We are grateful for the concepts included in this bill and are grateful to the chairs for listening to families.

While we support this bill in concept, The Arc has serious concerns about certain sections in Raised Bill 294 and offers support with these suggested revisions:

Recommendation 1

Section 1 Definitions:

(1) The definition of "waiting list": "Waiting list" means a list maintained by the commissioner that includes the names of individuals with intellectual disability who (A) have requested residential or day support services from the department, and (B) the commissioner has determined to be in urgent need for the services requested.

(5) The definition of "Priority status": "Priority status" means the code assigned to an individual with intellectual disability for whom services from the department have been requested that identifies the level of urgency of the individual's need for services.

The Arc recommends removal of these sections in their entirety for a number of reasons. The DDS Residential Waiting List and Planning Lists should never be combined. Period.

First the present definitions were developed as part of The Arc's Watling List Lawsuit filed in 2000 and settled in 2002.

Furthermore, The Arc and DDS are presently working together on a Waiting List Definition Working Group and will be making recommendations about waiting list definitions in the coming months. We believe the Public Health Committee should not vote favorably on this bill with the waiting list definitions sections as written and at the very least, should wait until after this working group has had the chance to thoroughly and thoughtfully recommend revised definitions. For more information about this working group feel free to contact myself or the Department of Developmental Services.

However, if the committee must move forward with this section The Arc proposes the following revision.

"Waiting List means a list maintained by the department that includes the names of individuals with intellectual disability who have requested residential, day support, or any other services from the department, and have either not received or received insufficient services. The department shall maintain separate lists for each service."

*Note that under the proposed statute, there is no requirement that people were actually denied services. Technically then, the list would include everyone who asked for services, including those who actually got what they wanted.

Recommendation 2

(c) (1) Not later than September 30, 2016, the commissioner shall notify, in writing, each individual with intellectual disability who is receiving services from the department, and the individual's parent, conservator, guardian or other legal representative of the individual's priority status and the amount of funding budgeted for each service provided by the department.

The notice in this section should be provided annually, not just one time. We want families to be annually informed of their status.

We recommend an amended section as follows: *"(c)(1) Not later than September 30, 2016, and annually thereafter, the commissioner shall notify, in writing, each individual with intellectual disability who is receiving services from the department, and the individual's parent, conservator, guardian or other legal representative of the individual's priority status and the amount of funding budgeted for each service provided by the department. Beginning September 30, 2017, the annual notification shall include the individual's up-to-date level of need assessment."*

Recommendation 3

(d) (1) On and after July 1, 2017, the commissioner shall update the waiting list not less than once every three years.

The waiting list is currently updated quarterly in the Commissioner's Management Information Report. We believe this subsection, calling for the waiting list to be updated once every three years, would be a step backward, and should be eliminated.

Recommendation 4

The Arc has heard repeatedly that DDS hearings are secretive proceedings. We have one family who actually refers to these proceedings at "The Star Chamber". Families receive decisions with no rationale, and when they seek documentation of the decision, they can't get them—even documents related solely to their own family member. We submitted language to be included in this bill to address this which was not included in the version I testify on today. We recommend the following addition be made to the bill before it is voted out of committee:

(add new) (f) Upon the request of any individual that has requested services or supports from the department, the department shall provide copies of any document used by the department that in whole or in part formed the basis for the department's decision. Documents shall be provided in accordance with HIPAA, but HIPAA shall not be used to deny access to the individual's own records.

Recommendation 5

Section 2: The list of Stakeholders should be amended to include *"individuals and families of individuals on the DDS residential waiting and planning lists"*

You have an incredible opportunity to give families some hope about the future of their loved one with an intellectual disability without costing the state money. The Department of Developmental Disabilities already has the necessary mechanisms in place to implement what this bill would require. They have the tracking infrastructure, the administrative staff and the ability to generate said reports from existing information technology.

The Arc urges the committee to vote favorably on Raised Bill 294 only with our suggested revisions and help our families move this important bill through the legislative process so it can pass and begin to make the lives of individuals with intellectual and developmental disabilities and their families a little easier.

Thank you.

**Proposed Language for The DDS Family Bill of Rights
(Submitted to Representative Mike Demicco and the Chairs of Public Health in February 2016)**

Summary or description of proposed legislation:

To amend the general statutes to require the Department of Developmental Services to (1) in any funding decision regarding direct services provide in writing (a) the dollar amount of the funding, if any, (b) the deadline to accept or reject the funding, (c) the consequences of accepting or rejecting the funding on the individual's right to receive additional services and/or maintain his or her place on the waiting list, and (d) the right to appeal the decision; (2) annually, on or before September 15, provide a written summary to each person receiving services that includes their level of need, classification on the residential waiting and planning lists, and current budget for each funded service; and (3) provide upon the request of any individual that has requested services or supports from the department, copies of any and all documents used by the department that in whole or in part formed the basis for the department's decision. Documents shall be provided in accordance with HIPAA, but HIPAA shall not be used to deny access to the individual's own records.

Statement of purpose:

To ensure that families are fully informed of their status as regards Department of Developmental Disability services, and the consequences of accepting or rejecting funding on the individual's right to receive additional services and/or maintain his or her place on the waiting list.

Why do we need a DDS Family's Rights Bill?

(Submitted to the Representative Mike Demicco and the Chairs of Public Health
February 2016)

The rationale for this bill is that people have a right to expect, in their dealings with DDS, they will at all times have the information they need to know their status within DDS, and to make informed decisions to best advocate for their children and loved ones. This means that any proceedings should be "regular"—that is, the same for everyone and following established rules and principles that are known to the participants and that the basis for decisions will be clearly stated in writing.

- Family members report that because DDS changes its standards to receive services without notice, it is impossible to know what information they must present to meet those standards. Moreover, because critical DDS decisions are made without the opportunity to attend, participate, or review evidence, families are frequently denied services without any explanation or rationale for that adverse decision. This makes it extremely difficult to pursue appeals to DSS.
- Family members also report that they are not provided with basic information on the consequences of accepting or rejecting offered funding/services by DDS; nor are they adequately advised that, for many services, there are deadlines by which they must either act or risk losing the funding. This information is critical, as a family's actions or failure to act can have serious consequences, including the potential loss of additional/future funding, and a change in the family member's placement on waiting lists.

